Pediatric Thromboprophylaxis Survey

Start of Block: Screening

Q1 Are you one of the primary **outpatient** pediatric thrombosis providers at your institution?

- Yes (1)
- No (2)

Skip To: Q2 If Are you one of the primary outpatient pediatric thrombosis providers at your institution? = Yes

Display This Question:

If Are you one of the primary outpatient pediatric thrombosis providers at your institution? = Yes

Q2 Does your institution have a dedicated pediatric thrombosis program?

- Yes (1)
- No (2)
- I don't know (3)

End of Block: Screening

Start of Block: Demographics

Q3 How many years have you been in practice?

- < 5 years (2)
- 5-10 years (3)
- >10 years (4)

Q4 What best describes your primary practice?

- Free standing pediatric hospital (1)
- Combined adult and pediatric center (2)
- Other (5) _____

Q5 What best describes the setting of your primary practice?

- Academic medical center (1)
- Non-academic/community based hospital (2)
- Private practice (3)
- Other (4) _____

Q6 In which country is your primary practice?

▼ United States of America (1) ... Zimbabwe (1357)

Q7 At your institution, do you currently have an ongoing IRB/ethics committee-approved prospective cohort study (or registry) of pediatric venous thromboembolism (VTE) in which long-term outcomes are captured?

- Yes (1)
- No (3)
- I don't know (4)

End of Block: Demographics

Start of Block: Provoked venous thromboembolism (VTE=DVT + PE)

Q8 Approximately how many children do you see each year with newly diagnosed provoked VTE (VTE=DVT + PE)?

- ○ < 20 (1)
- ○ 20 to < 40 (2)
- ○ 40 to < 60 (3)
- ○ 60 or more (4)
- ○ I don't know (5)

Q9 How long do you typically treat provoked VTE?

- ○ 6 weeks (1)
- ○ 3 months (2)
- ○ 6 months (3)
- ○ Other (4) _____

Q10 Do you perform thrombophilia testing on children with provoked VTE?

- ○ Yes (1)
- ○ No (4)
- ○ Sometimes (5)

Skip To: Q11 If Do you perform thrombophilia testing on children with provoked VTE? = Yes
Skip To: Q11 If Do you perform thrombophilia testing on children with provoked VTE? = Sometimes
Skip To: End of Block If Do you perform thrombophilia testing on children with provoked VTE? = No

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Q11 You indicated that you perform thrombophilia testing on children with provoked VTE. When do you typically perform testing?

- ○ Initial VTE (1)
- ○ Only if recurrent VTE (2)
- ○ Other (3) _____

End of Block: Provoked venous thromboembolism (VTE=DVT + PE)

Start of Block: Secondary Thromboprophylaxis-Prescribing Patterns

Q12 In recent years, what percentage of your pediatric patients with provoked VTE have had persistent prothrombotic risk factors upon completion of a conventional course of therapy?

- ○ None (1)
- ○ < 10% (2)
- ○ 10 - 30% (3)
- ○ > 30% (4)
- ○ I don't know (5)

Display This Question:

If In recent years, what percentage of your pediatric patients with provoked VTE have had persistent... = < 10%

Or In recent years, what percentage of your pediatric patients with provoked VTE have had persistent... = 10 - 30%

Or In recent years, what percentage of your pediatric patients with provoked VTE have had persistent... = > 30%

Q42 What percentage of those patients have received secondary thromboprophylaxis after completion of the conventional course of therapy?

- None (1)
- < 25% (2)
- >25 - 50% (3)
- > 50-75% (4)
- >75-100% (5)
- I don't know (7)

Display This Question:

If What percentage of those patients have received secondary thromboprophylaxis after completion of... = < 25%

Or What percentage of those patients have received secondary thromboprophylaxis after completion of... = >25 - 50%

Or What percentage of those patients have received secondary thromboprophylaxis after completion of... = > 50-75%

Q43 Among those who have received secondary thromboprophylaxis, which approach has been most common?

- Chronic daily anticoagulation, THERAPEUTIC dosing (1)
- Chronic daily anticoagulation, LOW DOSE, with increase to therapeutic dosing during times of additional acquired clinical prothrombotic risk factors beyond the patient's baseline persistent prothrombotic risk factor(s). (2)
- No chronic daily anticoagulation, but use of EPISODIC secondary thromboprophylaxis with low-dose anticoagulation during times of additional acquired clinical prothrombotic risk factors beyond the patient's baseline persistent prothrombotic risk factor(s). (3)
- OBSERVATION without secondary thromboprophylaxis. (4)
- I don't know (7)
- Other (5) _____

Q13

For each of the following prothrombotic risk factor scenarios, select the corresponding approach that best describes your management practice for children who have persistent prothrombotic risk factors after completing initial treatment. Secondary thromboprophylaxis with chronic daily anticoagulation, **THERAPEUTIC** dosing. Secondary thromboprophylaxis with chronic daily anticoagulation, **LOW DOSE**, with increase to therapeutic dosing during times of additional acquired clinical prothrombotic risk factors beyond the patient's baseline persistent prothrombotic risk factor(s). No chronic daily anticoagulation, but use of **EPISODIC** secondary thromboprophylaxis with low-dose anticoagulation during times of additional acquired clinical prothrombotic risk factors beyond the patient's baseline persistent prothrombotic risk factor(s). **OBSERVATION** without secondary thromboprophylaxis. If you select "other", you will be asked to elaborate on the next page.

	Chronic, THERAPEUTIC (1)	Chronic, LOW DOSE (2)	EPISODIC (3)	OBSERVATION ONLY (4)	Other (5)
Mild thrombophilia (e.g., heterozygous prothrombin or factor V Leiden mutations, protein C/S levels 20-40%, antithrombin levels 30-<65%) (1)	○	○	○	○	○
Potent thrombophilia (e.g., homozygous prothrombin or factor V Leiden mutations, protein C/S levels <20%, antithrombin levels <30%) (2)	○	○	○	○	○
Recurrent provoked VTE (3)	○	○	○	○	○
Recurrent unprovoked VTE (13)	○	○	○	○	○

Presence of underlying inflammatory disorder (e.g. inflammatory bowel disease, systemic lupus erythematosus, sickle cell disease) (4)	○	○	○	○	○
Chronic central venous catheter (5)	○	○	○	○	○
Family history of young onset or unprovoked VTE (6)	○	○	○	○	○
Chronic immobility (7)	○	○	○	○	○

Display This Question:

If For each of the following prothrombotic risk factor scenarios, select the corresponding approach... [Other] (Count) >= 1

Q14 You selected "other" as a management approach for one or more of the previous prothrombotic risk factor scenarios. Please explain.

_____

Q15 In which age group do you feel comfortable initiating secondary thromboprophylaxis? (select all that apply)

- [ ] Infancy (birth-2 years) (2)
- [ ] Children (> 2 years- 12 years) (4)
- [ ] Adolescents (>12 years- 16 years) (5)
- [ ] Teenagers (>16 years - (6)

Q16 Does d-dimer play a role in your decision to implement secondary thromboprophylaxis in pediatric patients with provoked VTE who have persistent prothrombotic risk factors upon completion of treatment?

- ○ Yes (1)
- ○ No (2)

End of Block: Secondary Thromboprophylaxis-Prescribing Patterns

Start of Block: Cases

Q17 A 4-year-old male with TPN dependent short gut syndrome is found to have a (line associated) non-occlusive thrombus of his right subclavian vein. He has had several central venous catheters (CVC) placed previously but no prior history of DVT. He has now completed 3 months of anticoagulation and repeat Doppler ultrasound shows resolution of the thrombus. What is your next step in the management of this patient?

- ○ Initiate secondary thromboprophylaxis with chronic daily anticoagulation at THERAPEUTIC dosing (1)
- ○ Initiate secondary thromboprophylaxis with chronic daily anticoagulation, LOW DOSE, with increase to therapeutic dosing during times of additional acquired clinical prothrombotic risk factors beyond his baseline persistent prothrombotic risk factor(s) (2)
- ○ No chronic daily anticoagulation, but use of EPISODIC secondary thromboprophylaxis with low-dose anticoagulation during times of additional acquired clinical prothrombotic risk factors beyond his baseline persistent prothrombotic risk factor(s) (3)
- ○ OBSERVATION without secondary thromboprophylaxis as he has completed appropriate treatment with complete resolution of DVT (5)
- ○ Other (please specify) (6) _____

Q18 How confident are you that the answer you selected is the best management approach?

	Not confident at all (1)	Somewhat not confident (6)	Neutral (7)	Somewhat confident (8)	Very confident (10)
Please select one (19)	○	○	○	○	○

Q19 A 5-year-old female with provoked DVT after MVA, in the setting of family history of multiple first-degree family members with VTE onset prior age 50 years, has completed 3 months of anticoagulation. She was found to have a heterozygous Factor V Leiden mutation. What is your next step in the management of this patient?

- ○ Initiate secondary thromboprophylaxis with chronic daily anticoagulation, THERAPEUTIC dosing (1)
- ○ Initiate secondary thromboprophylaxis with chronic daily anticoagulation, LOW DOSE, with increase to therapeutic dosing during times of additional acquired clinical prothrombotic risk factors beyond her baseline persistent prothrombotic risk factor(s) (2)
- ○ No chronic daily anticoagulation, but use of EPISODIC secondary thromboprophylaxis with low-dose anticoagulation during times of additional acquired clinical prothrombotic risk factors beyond her baseline persistent prothrombotic risk factor(s) (3)
- ○ OBSERVATION without secondary thromboprophylaxis as this is her first clot and she has completed appropriate treatment with complete resolution of DVT (5)
- ○ Other (please specify) (6) _____

Q20 How confident are you that the answer you selected is the best management approach?

	Not confident at all (1)	Somewhat not confident (6)	Neutral (7)	Somewhat confident (8)	Very confident (9)
Please select one (18)	○	○	○	○	○

Q21 An 18-year-old obese female is diagnosed with pulmonary emboli in the setting of use of estrogen containing oral contraceptive pills which were discontinued at the time of diagnosis. She has completed a conventional treatment course of anticoagulation. Repeat imaging shows resolution of thrombi. Thrombophilia work-up at the end of treatment is significant for Protein S level of 11%, persistent on repeat. What is your next step in the management of this patient?

- ○ Initiate secondary thromboprophylaxis with chronic daily anticoagulation, THERAPEUTIC dosing (1)
- ○ Initiate secondary thromboprophylaxis with chronic daily anticoagulation, LOW DOSE, with increase to therapeutic dosing during times of additional acquired clinical prothrombotic risk factors beyond her baseline persistent prothrombotic risk factor(s) (2)
- ○ No chronic daily anticoagulation, but use of EPISODIC secondary thromboprophylaxis with low-dose anticoagulation during times of additional acquired clinical prothrombotic risk factors beyond her baseline persistent prothrombotic risk factor(s) (3)
- ○ OBSERVATION without secondary thromboprophylaxis as this is her first clot and she has completed appropriate treatment with complete resolution of PE (5)
- ○ Other (please specify) (6) _____

Q22 How confident are you that the answer you selected is the best management approach?

	Not confident at all (1)	Somewhat not confident (6)	Neutral (7)	Somewhat confident (8)	Very confident (9)
Please select one (18)	○	○	○	○	○

Q23 Please rank the following future research ideas in pediatric VTE in the order you feel should be prioritized? (1-most needed)
_____ Determining optimal **intensity** of long term anticoagulation in children at high risk for VTE recurrence (1)
_____ Determining optimal **duration** of long term anticoagulation in children at high risk for VTE recurrence (2)
_____ Identifying risk factors that lead to the highest rates of VTE recurrence to ultimately develop risk prediction model (3)
_____ Other (4)

End of Block: Cases

Start of Block: Follow-up

Q24 If endorsed by the ISTH Scientific and Standardization Committee's Pediatric Subcommittee, and on a REDCap web-based data entry platform, I would participate in a multicenter prospective cohort study of pediatric patients with provoked VTE in whom secondary thromboprophylaxis is prescribed. The key aims of such a study are describing characteristics of the patient population and indications for secondary thromboprophylaxis along with investigating efficacy and safety outcomes.

- ○ Yes (1)
- ○ No (2)

Skip To: End of Survey If If endorsed by the ISTH Scientific and Standardization Committee's Pediatric Subcommittee, and... = No

Skip To: Q25 If If endorsed by the ISTH Scientific and Standardization Committee's Pediatric Subcommittee, and... = Yes

Display This Question:

If If endorsed by the ISTH Scientific and Standardization Committee's Pediatric Subcommittee, and... = Yes

Q25 Provide your contact information below to express interest in participating in the multicenter cohort study of Duration of Therapy for Thrombosis in Children-Secondary Thromboprophylaxis Evaluation for Persistent Prothrombotic States (Kids-DOTT-STEPPS).
No personal information will be linked in any way to your survey responses.

- [ ] Name (11) _____
- [ ] Institutional Affiliation (12) _____
- [ ] Email (13) _____

Skip To: End of Survey If Condition: Provide your contact inform... Is Greater Than or Equal to 1. Skip To: End of Survey.

End of Block: Follow-up